EPIDEMIOLOGY OF MUNCHHAUSEN SYNDROME BY PROXY AND IMPROVING PHOTOGRAPHY OF INJURIES

Rebecca Rodriguez-Pou MD FAAP

First Coast Child Protection Team
University of Florida - Jacksonville
INCIDENCE OF MUNCHHAUSEN SYNDROME BY PROXY IN THE UNITED STATES
MUNCHAUSEN SYNDROME

- Named after Baron Von Munchausen, a European teller of tall tales
- Children’s books exist in Europe based upon these fantastic confabulated tales
- First described by Ascher in 1951
MUNCHHAUSEN SYNDROME

- Typically by adults - making up medical stories about themselves
- Fabricated stories about illness
- Production of symptoms/signs is common
- Multiple surgeries/hospitalizations often occur
MUNCHHAUSEN SYNDROME BY PROXY THE HINTERLAND OF CHILD ABUSE

Roy Meadow

- Department of Paediatrics and Child Health, Seacroft Hospital, Leeds, United Kingdom
- THE LANCET Volume 310, Issue 8033, 13 August 1977, Pages 343-345
SPECIFIC DEFINITION OF MUNCHAUSEN SYNDROME BY PROXY

- Apparent illness or health-related abnormality which the caretaker made up or produced
- Presentation of the child for medical treatment
- Failure of the perpetrator to acknowledge the deception
- Exclusion of simple child abuse/neglect and simple homicide
CONVENTIONAL WISDOM
CAREGIVER-FABRICATED ILLNESS IN A CHILD

- Males and females are victimized equally.
- The median age at diagnosis is between 14 months and 2.7 years.
- Most of the victims are infants and toddlers, although approximately 25% of cases occur in children older than 6 years.

CONVENTIONAL WISDOM
CAREGIVER-FABRICATED ILLNESS IN A CHILD

► It is considered a relatively rare condition
► Hundreds of articles in the medical literature
► Thousands more cases known.

LITERATURE REVIEW

- Annual incidence of at least 0.5 per 100,000 children younger than 16 years of age in the United Kingdom and the Republic of Ireland¹.

- Annual incidence of 2 per 100,000 children younger than 16 years of age and 1.2 per 100,000 children younger than 16 years reported to child protective services in New Zealand².

- Unsuccessful in finding an estimated incidence for Munchausen syndrome by proxy for the United States.


PURPOSE OF STUDY

- Establish an estimated incidence of Munchausen syndrome by proxy in Florida.
- Extrapolate Florida results for an estimated national incidence.
- Does the incidence change over time?
METHODS

- Descriptive epidemiology study.
- Data collected from Florida’s single statewide child abuse/neglect data bank - Child Protection Team Information System (CPTIS) within the Department of Health.
- In Florida, all child abuse/neglect cases that are reported to CPS are evaluated by one of the 22 Child Protective Team (CPT) offices that handle all 67 counties in this state.
- All cases of abuse by Munchausen syndrome by proxy diagnosed in Florida are mandatory for CPT to see, and are documented in CPTIS.
PHASE 1

- The term routinely utilized in CPTIS is Munchausen syndrome by proxy.

- Inclusion criteria:
  - Medical reports with an impression of abuse by Munchausen syndrome by proxy.
  - Child victims 0 to 216 months old.
  - Demographic data for the victim (gender of victim and age).

- Exclusion criteria:
  - Child victims older than 216 months old (18 years old).
PHASE 1

A comparison of the incidence of MSBP in the State of Florida to the incidence of head trauma cases in the state during the same time period.

Second CPTIS data run:

- Child victims 0 to 60 months old diagnosed with head injury including all of the different subcategories during the same time frame.

Subcategories of interest:
- Retinal hemorrhage
- Whiplash-shaking syndrome.

“Abusive head trauma” is not a category in CPTIS.

Incidence of MSBP, retinal hemorrhage and whiplash-shaking syndrome were compared to determine the relative ratios.
RESULTS:
PHASE 1

- 163 confirmed cases of Munchausen syndrome by proxy in the State of Florida for children younger than 18 years of age during January 1, 2010 to December 31, 2020.
- 31% were younger than 5 years of age.
- Prior studies established a decreased incidence among the adolescent population which was not seen in Florida data.
- Equal gender.
  - 49.5 % male child victims
  - 51.9 % females child victims
RESULTS: PHASE 1

Distribution of age at time of diagnosis

MEDIAN AGE = 93 months
RESULTS:
PHASE 1

- Data collected for head trauma in Florida by the CPTIS system is recorded under certain subgroups. The subgroups of interest were coded as: “retinal hemorrhage” (RH) and “whiplash-shaking syndrome” (WSS).

- **323** confirmed cases of **RH** for children < 18 y/o and **303** confirmed cases for children < 5 y/o.

- **169** confirmed cases of **WSS** for children < 18 y/o and **166** for < 5 y/o.
RESULTS:
PHASE 1

- Average annual incidence from 2010 to 2020 for < 18 y/o:
  - MSBP: 0.36/100,000
  - RH: 0.67/100,000
  - WSS: 0.37/100,000
- Ratio MSBP:RH:WSS: 1:2:1
RESULTS:
PHASE 1

Average annual incidence from 2010 to 2020 for < 5 y/o:

- MSBP: 0.44/100,000
- RH: 2.51/100,000
- WSS: 1.37/100,000

Ratio MSBP:RH:WSS: 1:4:2
RESULTS: PHASE 1

- Poisson regression during the 11 year time period the incidence rate of MSBP increased by a factor of 0.06581.
  - Increase in the total cases per year by ~1 case
  - Significant (p = 0.01).
- No significant change in the incidence for retinal hemorrhages and whiplash-shaking syndrome.
- No effect of COVID on a year to year basis.
RESULTS:
PHASE 1

3 year increments MSBP vs. RH vs. WSS

- MSBP counts
- Retinal Hemorrhage
- Whiplash-Shaking Syndrome
Estimated incidence of MSBP and AHT according to physicians practicing in child abuse medicine nationwide was sought out by an anonymous RedCap survey among Ray E. Helfer Society.

The Ray E. Helfer Society was founded in 1999 and is the primary sub-specialty society for physicians dedicated to the problem of maltreated children.
PHASE 2

Intent was to establish a ratio of MSBP cases vs. AHT cases identified in these centers from 2015 - 2020.

Inclusion criteria:
- Ray E. Helfer Society listserv member
- Practicing child abuse medicine
- In the US and its territories

Exclusion criteria:
- Principal investigator and co-investigators
- Outside the United States.
PHASE 2

- This ratio was established for Florida using CPTIS data and was compared with the Helfer listserv survey data.
- The purpose of this survey was to answer the same question with more than one approach.
RESULTS:
PHASE 2

- 31 RedCap surveys were completed by Ray E. Helfer Society listserv participants. Response rate of 5%.

- Average number of cases of AHT:
  - Past 5 years were 75 cases
  - Past year were 15 cases

- Average number of cases of MSBP:
  - Past 5 years were 15 cases
  - Past year 3 cases 15 MSBP cases

- Median and mean ratio for AHT to MSP of roughly 5:1.
DISCUSSION

- MSBP is considered a relatively rare condition:
  - Incidence of 0.5/100,000 children <16 y/o in the UK and Republic of Ireland (1992-1994)
  - 2/100,000 children <16 y/o, of those 1.2/100,000 were reported to CPS in New Zealand (1999).
  - This is the first US incidence study to our knowledge
  - During the 11 year study period average annual incidence of MSBP was 0.36/100,000 for children <18 years of age.
  - Contrary to previous studies, MSBP well represented at all ages.
  - Small increase of MSBP year to year.
  - No COVID effect.
DISCUSSION

- Incidence ratio for MSBP to RH to WSS is 1:2:1 for children <18 y/o.
- Incidence ratio for MSBP to RH to WSS is 1:4:2 for children <5 y/o.
  - Similar to RedCap survey response: Ratio for AHT to MSBP of 5:1.
DISCUSSION

- Limitations:
  - Coding issues regarding diagnosis.
  - Subjective estimates of cases seen.
  - Differences in precision for diagnosing AHT and MSBP cases that were suspected versus verified.
  - Relatively low response rate.
DISCUSSION

Strengths:

- Data from the 3rd most populous state.
- 11 year time period.
- Not based on single hospital or a set of hospitals
- Comparable training and extensive peer review.
DISCUSSION

- Comparing Florida data with estimates from other places in the US.
- Two methodologies:
  - *Phase 1*.
    - Florida average around 15 cases of MSBP per year.
    - Florida population <18 y/o was 4,198,955.
    - US population <18 y/o was 73,296,738.
    - National estimate of 262 cases MSBP per year.
  - *Phase 2*.
    - Estimated ratio of AHT and MSBP (5:1).
    - AHT incidence in the US 1300 cases per year.
    - National estimate of 260 cases MSBP per year.
PHOTODOCUMENTATION FOR
PHYSICAL ABUSE CASES
THE ROLE OF PHOTODOCUMENTATION

In the field of child abuse pediatrics, photodocumentation of a cutaneous injury is a standard of practice. Photodocumentation enables peer review, expert consultation, research, teaching, and testifying in legal proceedings.

Various legal rules and opinions govern the use of photographs in court. The key is that the photograph reasonably depicts what the witness observed, or that it reasonably stands on its own.

If the examiner’s impressions differ from the photographs, it is important that this be made apparent.
IS IT OK IF I TAKE A PICTURE?

- The taking of photographs without parental consent is allowed in ALL STATES as part of the child abuse reporting laws dating back to the 1970’s.
- The purpose is to allow an investigation without interference if the parent or guardian is possibly the perpetrator or would confound the investigation.
- Typically does not require a court order.
- Entities that take photographs in these situations are: child protective services (CPS), law enforcement, and medical authorities.
AUTHORITY TO TAKE PHOTOGRAPHS

- Florida Code 39.304 Photographs, medical examinations, X-rays, and medical treatment of abused, abandoned, or neglected child.

- (1)(a) Any person required to investigate cases of suspected child abuse, abandonment, or neglect may take or cause to be taken photographs of the areas of trauma visible on a child who is subject of a report. Any child protection team that examines a child who is the subject of a report must take, or cause to be taken, photographs of any areas of trauma visible on the child. Photographs of physical abuse injuries, or duplicates thereof, shall be provided to the department for inclusion in the investigative file and shall become part of that file. Photographs of sexual abuse trauma shall be made part of the child protection team medical record.
PHOTOGRAPHY QI PROJECT: METHODOLOGY

- 70 PI photo sets
- Reviewed
- Intervention
- 25 photo sets
- Review
- Final Report
Photo Documentation Assessment Tool

Case # _______________________

Photo Set
Lesion and location: ____________________________________________________________

Of the photos depicting the designated lesion, are the following demonstrated?

- Excellent lighting for photo set □ YES(1) □ NO(0)
  Comment ________________________________________________________________

- At least 1 photo taken perpendicular (at 90° angle) to lesion □ YES(1) □ NO(0)
  Comment ________________________________________________________________

- Body location identifiable
  Perspective photo (entire lesion in focus with body part identifiable) □ YES(1) □ NO(0)

  Mid distance between perspective and close up photo □ YES(1) □ NO(0)

  Close up photo □ YES or NA(1) □ NO(0)
  Comment ________________________________________________________________

- Scale present AND in same plane(s) as lesion (scale same distance from camera as lesion)
  □ YES or NA(1) □ NO(0)
  Comment ________________________________________________________________

- Close up picture with and without scale □ YES(1) □ NO(0)
  Comment ________________________________________________________________

Please rate the overall quality of the photo set

□ Inadequate (1): Photos do not depict the finding well enough to use in teaching
□ Would not use in a national peer review/court

To be filled out by Dr. Rodriguez-Pou
Was it documented in the medical report that the child difficult to photograph
□ YES(1) □ NO(0)
□ Inadequate (1): Photos do not depict the finding well enough to use in teaching
□ Would not use in a national peer review/court

□ Excellent (3): Photo set is of a quality that would make you proud to use the finding in a national peer review/court

□ Adequate (2): You would be willing to use the finding in a national peer review/court but you would be tempted to explain why the photo(s) are less than ideal

Total out of 7 possible
PRE-INTERVENTION FINDINGS

OVERALL PHOTOSET QUALITY

Reviewer #1

Reviewer #2

Excellent
Adequate
Inadequate
FINDINGS

- Most common issues:
  - Too few pictures - Average number of pictures taken per injury: 2.89.
  - Blurry picture
  - Poor lighting
  - Photo card in front of injury/Not on the same plane.
  - Photo card is bent.
  - No true perpendicular picture.
SHOW ME WHAT YOU’RE WORKING WITH!

Nikon D3200, D3400, D5600
TAKE HOME MESSAGE AT INTERVENTION

- In order to collect quality photos remember the following:
  - Be mindful of lighting and use it to your advantage.
  - Consider depth of field.
  - Wait for the camera... press the shutter button halfway.
  - Can you identify what is in the photograph? Can other people identify what is in the photograph?
  - Take multiple photos at 3 different distances.
  - Use the ABFO or a ruler to show the camera the point of interest.
  - If all else fails revert to autofocus.
POST-INTERVENTION

- Conducted 1 month after intervention.
- 25 photosets created with equal representation of CPT medical team.

Findings:

- Average number of pictures taken per injury: 5
- Improvements - Focus, lighting, use ABFO
RESULTS

AVERAGE SCORES PRE AND POST

Reviewer #1
Pre-Intervention
Post-Intervention

Reviewer #2
Pre-Intervention
Post-Intervention
A QI project on photography can improve photodocumentation of injuries in the child abuse setting.

This project demonstrated improvement in technique and overall quality of photography.

It is likely that there is a need to repeat training over time.

Future training could include:
- Improvements in lighting.
- Teaching how to use manual focus at times when auto focus does not work well.
- Continued peer review of photos.
- Consider use of video.
QUESTIONS?

Thank you.